THE ETHICAL ISSUE BEHIND HEALTH CARE RATIONING WITH SPECIAL CONCERN FOR MENTAL HEALTH

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ABSTRACT.

Human being has a tendency to use more resources than are available. More and more countries spend almost all their economic growth on health services and education. Yet the public do not feel that the huge increasing of funding allocated to health has produced a significant change. In fact, it comes out in surveys that people are more concern about whether or not they will be able to access health services when they or their family members need it than the quality of those services.

AIM. This paper offers an ethical interpretation of health care rationing. How can we justify the choices of prioritizing a patient before another one? How far can we go? Should we only take into consideration the stage of the sickness? Why not age, capacity to benefit from the treatment, and merit-consideration? In addition another issue is rising: how can we apply these criteria in mental health care?

METHODOLOGY AND RESULTS. This paper is focused on psychiatrically health services for children. I tried to capture the opinion of decision-makers and to understand the process of evaluation of referrals to children psychiatric clinic. I interviewed three decisions makers and I followed the process of evaluated the referrals from family doctors. I decided to present five patient cases that, in my opinion are most representative for children psychiatry and to projects. One aims to find out how different decision makers from different clinics evaluate same referral and the other one measures how good are the referrals from family doctors. Although the results are not representative for the general population, there are significant differences, which should at least raise some ethical questions.

LIMITATIONS. A social perspective upon an economical aspect struggles always to capture rational attitudes. The truth is we are more likely to be rational about sexual desire than spending money.

CONCLUSION. The topic is on debate since Euripides' time and I do not pretend that I can solve it hic et nunc. When it comes to our responsibility towards other people, personal sense of justice seems to be a “good enough” way to deal with it.

Key words: ethics, health care system, mental health, quality, rationing, resources.

SUMMARY

MOTTO

You cannot strengthen the weak by weakening the strong.
You cannot help small men by tearing down big men.
You cannot help the poor by destroying the rich.
You cannot lift the wage earner by pulling down the wage payer.
You cannot keep out of trouble by spending more than your income.
You cannot further the brotherhood of man by inciting class hatreds.
You cannot establish security on borrowed money.
You cannot build character and courage by taking away a man's initiative and independence.
You cannot help men permanently by doing for them what they could and should do for themselves.

William J. H. Boetcker, 1916 (often attributed to Lincoln)

FOREWORD

I want to ensure whoever might read this paper that I do not aim either to solve the problem, or to hold responsible anybody for any shortcut the system shows, but to raise ethical questions and to increase awareness among those that are interested in this issue: prioritizing in health care services.

It is something with the rationing policy that it is not entirely right, especially in a socialist system that is calling itself and that is generally viewed as the welfare state like the Norwegian state. People know that they pay their taxes every month, religiously and they expect to benefit from the common wealth when they might need it. Yet, miracles happenes and people, some of us at least, end up on waiting list or even worse, ending up waiting in vain.

The politicians present an image that underlines the positive aspects of the system and forget to mention that sick people wait in line for months in order to receive treatment. In some cases, we find out that from media that they wait in line until they did not need the share of welfare anymore.

The world envies Norway. And blame the America. But really what is the difference?!

I want to thank to everybody who was involved in the process and a special thanks to my friend Bjørn who did experience to be denied the right to specialized health care despite his illness and the pain he has to endure.

CHAPTER ONE

INTRODUCTION

THEME. This paper treats the ethical issues behind health care rationing with special concern for mental health. In this part of the paper, I shall present the background of this theme, the approach that I have chosen, the plan of the paper and the limitation of the study.

BACKGROUND. Health care rationing is definitely an unpopular theme. When the system is based on a liberal principle and the population have access to health care services based on the type of private insurance that they purchase, the health care is rationed automatically by the individual's ability and willingness to pay. Even so, the public media comment upon the ethics of such a system. The humanitarian perspective will always argue that willingness-to-pay is not so much a question of 'will' but a question of 'can': can I pay the fee for my insurance policy or not? If I "can" but I "will" not, than it is my problem and nobodies else's problem. What if I "will" but I "can" not, what is to be done? Should we, who have both the willingness-to-pay and ability-to-pay let the others die just because they are not as lucky as we are? After all these years of evolution and progress of human rights, are we ending up in the same old 'live and let die' philosophy? We like so much to throw charity balls to raise money for children in some other part of the world but when it comes to our neighbor's children we do not give a… thing!

In the socialist system, on the other hand, everybody is paying taxes and supposedly, everybody has the same right to access health care. Theoretically, we have here the perfect equation. People gives, people receives. People know that they pay their taxes every month, religiously and they expect to benefit from the common wealth when they might need it. However, the reality is not that serene. The politicians present an image that underlines the positive aspects of the system and forget to mention that sick people wait in line for months in

order to receive treatment. In some cases, we find out that they wait in line until they do not need the share of welfare anymore. Even in social health care, we talk about rationed health care and patients prioritizing because of limited resources. It is something with the rationing policy that it is not entirely right, especially in a social system that is self-proclaimed the welfare state like the Norwegian system. And it does not seem to be a money-related problem. More and more countries, including Norway spend almost all their economic growth on health services and education. Yet, the public do not feel that the huge increasing of funding allocated to health has produced a significant change. In fact, in surveys people do show a real concern about the quality of health services but they are even more concerned about whether they will be able or not to access health services when they or their family members need them.

So, if the medical system is consuming more and more resources, yet people are treated less and less, it might be a problem of allocation of funds. Human beings have a tendency to use more resources than are available. Patients demand more and more from their doctors, a more advanced treatment, better conditions, bigger rooms and why not counseling – economical, psychological, juridical. But it is not only patients that demand. A disease, an accident is a problem that affects the entire family, community, society. In addition, the medical personal demand more from the system, more advanced medical technology, better conditions, and bigger salary. So the medical system becomes the girl with golden hair. Everybody wants some. And in order to make sure that she does not end bald-headed we pay some decision makers to solve the problem. The easy solution is to limit the access to the golden-hair lady. They cannot dare to suggest neither cutting off salaries or benefits, nor to suggest limitation of progress in science. We shall end up doing the best for a handful of people: economists, doctors, other medical personal and some patients. Yet how shall we decide which patient is lucky enough in order to benefit from the available resources? We hire other specialists to decide who will gain most from the treatment, which treatment is most cost-effective, and which patient will reward most the society once he or she will recover. It looks like a qualitative human selection all over again, but instead of talking about the superior race, is talking about the superior individual.

Since 2oo8 the Norwegian health department has created 32 guides in order to regulate access to health care and, arbitrarily or not, the guides for mental health care were among the first ones. I cannot help wondering how many Norwegians heard about them. There was no

campaign to promote them among the general public. Nobody mentions them: neither the health minister's officials nor the media. Only one association, the one of people with hearing impairment (Hørselshemmedes Landsforbud) commented upon and suggested modifications to the guide for the benefit of this specific group of people. It has not come to my knowledge whether The Norwegian Health Department (Helsedirektoratet) has taken into consideration those comments and suggestions, since no official answer has been given to the said association. And the guide has not been changed yet.

AIM. This paper aims to offer an ethical interpretation of health care rationing. How can we justify the choices of prioritizing a patient before another one? How far can we go? Should we only take into consideration the stage of the sickness? Why not age, capacity to benefit from the treatment, and merit-consideration? In addition another issue is rising: how can we apply these criteria in mental health care? How could you tell to a person who has just been diagnosed with mild depression that, according to the Norwegian guide for mental health services he/ she does not have the right to be prioritized?

METHODOLOGY AND RESULTS. A semi-structured interview was designed in order to put the questions above under evaluation from the decision-makers perspective. Although everybody agrees that nobody should wait for treatment, there are significant differences when it comes to judge and justify the waiting list.

LIMITATIONS. A social perspective upon an economical aspect struggles always to capture rational attitudes. The truth is that we are more likely to be rational about sexual desire than spending money. In addition, this paper is mostly based on qualitative methods and therefore it is not representative for general population. The opinions expressed by interviewers in this study might well be shared by others decision makers in mental health, or the data registered in Hedmarks psychiatrical clinics might be similar to data in others Norwegian clinics, but it is not the aim of this paper to prove that.

CONCLUSION. The topic is on debate since Euripides' time and I do not pretend that I can solve it hic et nunc. When it comes to our responsibility towards other people, common sense seems to be a way to deal with it. I remember an interesting statement that came from a mental patient who said: 'everybody is talking about how to reduce involuntary hospitalization of mental patients, but nobody realizes that these waiting lists 'are forcing' involuntary hospitalization’.

CHAPTER TWO

THE NORWEGIAN HEALTH CARE SYSTEM

1. Organization of Health Care System in Norway[1]

Norway, with a population of 4.6 million people living in an area of 386 958 Km^2 had the life expectancy at birth in 2004 of 77.5 years for males and 82.3 years for females, and they spend more than 10% of GDP on health.

As any other Scandinavian country, Norway is a monarchy that gained its independence in 1905, but the parliamentary form of government was establish based on constitution ever since 1814. Today there are three levels of government: national, councils and municipalities.

Health services are divided mainly between councils and municipalities. The first are responsible for the hospitals and specialized medical services, whereas municipalities are responsible for nursing homes and primary health services.

In 1999 five health regions were established, and they became four in 2007 by merging together the two largest region – East and South, as an intermediary level between the state, i.e. the national level of government and councils, and each region has its own university hospital.

- Health region North of Norway (Helse Nord): Finnmark, Troms og Nordland with more than 460,000 inhabitants;
- Health region Center of Norway (Helse Midt): Nord-Trøndelag, Sør-Trøndelag og Møre og Romsdal with almost 650,000 inhabitants;

[1] The information in this part of the paper are collected from the repport written by Jan Roth Johnsen - *Health Systems in Transition* - Printed and bound in Great Britain by TJ International, Padstow, Cornwall, 2006, pg.89-119

- Health region West (Helse Vest): Sogn og Fjordane, Hordaland og Rogaland with almost 1,000,000 inhabitants;
- and Health region South-East (Helse Sør-Øst): Akershus, Aust-Agder, Buskerud, Hedmark, Oppland, Oslo, Telemark, Vestfold, Vest-Agder og Østfold with more than 2,570,000 inhabitants.

We can talk about three different steps in the Norwegian medical service: the general practitioner (GP), the specialized doctors and the hospitals. The general practitioner is the gatekeeper for specialist doctors and for hospitals. If there is not an emergency case, patients contact the regular general practitioner and if there are any medical reasons they will make an appointment on their patient behalf to the appropriate caregiver or they will give a medical referral to the patient that can arrange herself/ himself an appointment with a specialist, radiology centre or a hospital. In case of emergency the patient is going or is sent directly to the emergency units of the nearest hospital.

The private sector in Norway is situated mainly in urban area and it is better represented in substance abuse treatment, rehabilitation, dental care, radiology and laboratory services and pharmaceutical industry. Otherwise, only 2% of somatic hospital beds are found in private hospitals and only 3% of the nursing homes are commercially run.

Co-payment for medical care[2]. The Norwegian health system is a tax-based system and up to 85% of the medical bill is covered by tax. In addition to taxes, the population pays a per cent from medical bill, which made the system a combination between tax and out-of-pocket payments. Here are some examples:

- for GP consultation during the day the person has to pay 136kr; if the consultation is taking place in the evening the price rise to 229kr;
- if the GP is a specialist than the person will pay 180kr during the day and 269 during the night;
- if you need a psychological session for 1 hour you will pay 307kr;
- if the doctor prescribes partial reimbursed medicine, the patient will pay 38% of the bill, but not more than 520kr;

[2] http://www.helfo.no/privatperson/egenandeler/Sider/default.aspx

There are some limits though. If the patient has paid out-of-pocket 1,880kr for medical services, then he or she shall receive a free card for the rest of the calendar year. This card it not valid for physiotherapy or for medical services bought outside of Norway. In this case, the patient will receive a free card after he or she has paid 2,560Kr.

Medical services that are considered unnecessary treatment are not counted in order to obtain free card, and the person has to pay the entire bill. Some examples:

- infertility treatment within three attempt will cost 1,500kr;
- sterilizing of men 1,268kr;
- sterilizing of women 6,079kr.

Otherwise, children under 16 do not pay for medical services that are calculated in order to obtain the first free card (1,880kr) and children under 18 and HIV patients do not pay for psychological treatment. In addition, every Norwegian citizen has free access to any public hospital in Norway and receives free of charge any necessary home nursing or assistance.

Health personnel and patients[3]. According to the Norwegian Statistics (Statistisk Sentralbyrå i Norge) in 2oo5 there were 288,765 registered medical personnel, out of which 270,314 were employed, 15,622 were independent or self-employed, 2,829 were out of work, and there were 838,633 patients in hospitals, psychiatric homes and maternal and child clinics. There were 15,282 doctors in Norway in 2005 and almost 4,000 of them were general practitioners. Approximately 99% of the population is registered on the general practitioner list. In the same year[4]. 52,325 persons contacted their family doctors. 26 440 (50.53%) of them contact their doctors only once, 10,959 (21.03%) twice and the rest of 14,926 (28.44%) three times and more. All those consultations resulted in 109,826 main diagnoses, out of which 13,469 (12.26%) were mental disorders and psychical syndromes. Among the most frequent psychological symptoms that the Norwegian people are complaining about are depression, tiredness / listlessness, anxiety and fear, insomnia. In addition, many people declare that they have been drug or alcohol addicts. More than twice as many women, by comparing them with men, have declared that they suffer from depressive symptoms or/and

[3] Statistics Norway (Statistisk Sentralbyrå) 2011 © Statistisk sentralbyrå, http://statbank.ssb.no/statistikkbanken/Default_FR.asp?PXSid=0&nvl=true&PLanguage=0&tilside=selectvarval/define.asp&Tabellid=06349; see the appendix 1

[4] I choose the year 2005 because it is the latest year with a complete statistic base of information

anxiety, while men are abusing far more often of substance or/and alcohol. Unfortunately, some of these people suffering from psychological illness are ending up committing suicidal acts. In 2005, 533 people (360 men and 173 women) took their own life and it has been estimated that between 6,000 and 8,000 people per year do attempt or at least seriously consider killing themselves.

Mental health. It is a tendency among some researchers to consider that psychological problems are increasing in the modern society, while another part pointed out that it is not increasing the number of psychical illnesses but the freedom to talk about them. Very good examples in this sense are the sexual problems like impotence or frigidity. For a century ago, discussing freely about psychical symptoms, especially sexual ones was a taboo and a shame for most people.

However, steady increasing numbers in the most recent years make it easy to believe that both parts have right. Norwegian Statistics showed that in 1999 the number of medical certificates with a mental illness as the main diagnostic has risen with 150% in the late 5 years, from 24,000 to 62,000 in the mentioned year.

The White Paper[5] issued in 1997 analysed the mental health services in Norway and showed that, at least at that time, there were problems with respect to preventive measures, access to specialized services, mental health services per se and follow-up and routine after discharge.

In 1998 the Norwegian Parliament implemented a reform in order to create a multilevel well-functioning system easy to access by all people suffering from mental illness:

- mental hospitals with specialized functions
- community mental health centre (distriktspsykiatriske sentre - DPS)
- private practicing psychiatrists and psychologists.

In addition, we find out that about 15% of the adult population and between 10 and 20% of children suffer from serious mental problems. Different researches showed that there is an

[5] *** Prescriptions for a Healthier Norway. A broad policy for public health. Report No.16 (2002-2003) to the Storting, the Ministery of Social Affairs, The Departement of Health (Helsedepartementet), http://www.regjeringen.no/Rpub/STM/20022003/016EN/PDFS/STM20022 0030016000EN_PDFS.pdf

increasing tendency of obesity, drug and alcohol abuse, smoking and one of five young persons complains about life issues that affect their life quality.

In order to prevent the amplification of those tendencies, it has become a priority in Norway to develop campaigns in order to prevent the risk of disease in general and mental disorders especially. In this sense a several reforms have been implemented[6]:

- regular general practitioners scheme
- transfer of responsibility for the specialist health services to the State
- Escalation Plan for Mental Health
- Mental Healthcare Act
- Patients' Right Act, and so on.

Of all these, maybe the most important is the Escalation Plan for Mental Health that has the main objective to prevent mental problems among the population and especially among children. As a follow up there has been created in 2003 a National Plan for Self-Help. Basically, the plan will bring into focus and increase awareness about the self-help tool. A self-help tool is more available, definitely cheaper than an external help and probably an even more appropriate help than some professional services. A person that has knowledge of how to help himself/herself in a critical situation has more chances to overcome the psychological difficulties related to that situation than a person that has to wait for medical services. Even more, that individual will gain a higher self-esteem and a lower dependency than a person without such a self-help tool.

In addition, the Mental Healthcare Act promotes the principle of human rights and by this voluntary treatment instead of coercion, if possible. However, when it is not possible, the decision is made by the physician, psychiatrist or psychologist and not based on family or a public official formal request. Therefore the decision regarding compulsory admittance to a hospital of a patient is taken after the patient was examined by two independent physicians.

The health care system's objective. The same report[7] mentions that the national goal is the distribution of health based on equality, justice and solidarity. "Through a strong public and

[6] Idem 5, pg. 14-15

[7] Idem 1, pg. 143-154

political consensus the main institutional strategy to meet the goals has been to offer universal coverage of high-quality health care services according to the needs, with equal access for equal needs, regardless of gender, social background, personal economy and geography."[8]

Later in the report, we find out that the main challenge in the distribution of health services in Norway is to recruit health personnel for rural areas. In addition, most hospitals are situated in urban area. The government tries to keep a balance between the rural and urban area by financing a large network of ambulance transportation by land, air and sea.

The second major challenge in Norway is related to the first and it is the allocation of resources both vertically and horizontally.

In the vertical allocation the major challenge is to balance between primary medical care and specialist health care. In addition, there are inequalities between groups of patients with respect to allocation of resources for new technology. As follows, elderly people, those suffering from chronic disease or mental disorders are not highly prioritized.

In the horizontal allocation of resources, there are inequalities between the urban and rural areas and the scattered population. The challenge is to provide primary care facilities in the rural areas even though is more expensive to do it than in the urban areas.

Another challenge is to reduce health inequalities related to socioeconomic indicators. It seems that in Norway, as in other western countries, health improves while an individual moves up the social scale, those in the lowest part of the scale are worst off. Therefore, while the health of the population as a whole is improving, the inequalities in health due to social inequalities are increasing in the same time.

However, it is very difficult to estimate and provide necessary health care, and even though Norway spends 45%[9] more per capita than her Swedish neighbour and 65% more than the OECD countries, it does not seem to be enough.

[8] Idem 1, pg. 143

[9] Idem 1, pg. 149

2. The Other Side of the Health Services

The individual is always superior to the group, Gustave Le Bon said.

If we accept this axiom, we can understand why neither system is good enough for anyone. The socialist system is too strict, the capitalist one is too liberal. People complain no matter what. We want the benefits from socialism and the freedom from capitalism, simultaneously. If we would have been able to do that, we could have seen how utopia looks like in the real life. In the meantime, it can be useful to find the best in what we have. We can complain about the state, the system, the government and so on, but that will never help. In the best-case scenario our complains will have some positive results for a short term. In the end, the system will recover itself and reconstruct its balance. Whoever follows the history tracks knows that there is no good without evil.

The Norwegian system is by definition socialist. The individual's actions shall seek the welfare of the society. The well-being of one particular person comes always the second and the government should promote acts and regulations that will serve best the majority as a group.

How is that influencing the health care system? What is the price an individual has to pay in order maintain a good health of the society? Which principle should rule equality or equity?

Tore Sæter and Vigdis Heimly from KITH – The Norwegian Center for IT Knowledge in Health Care and Social Sector – wrote a report[10] in 2006 regarding the public health service in Norway.

According to this report, the Norwegian health service is public, national and it is for everybody. In a welfare state, health along with social and economic security are main conditions to be satisfied. And that is why those services should be available to its every single citizen. Latter we find out that more that 95%[11] of the total costs associated to medical services are covered by the State.

[10] Tore Sæter, Vigdis Heimly – *En kort beskrivelse av helsevesenet i Norge. Tjeneste, enheter og organisering, trender og tall* – KITH Norge, 1996, http://www.kith.no/upload/2154/R13-96HelsevesenetNorge.pdf

[11] According to Jan Roth Johnsen (*Health Systems in Transition*, 2006) this percent is much lower

One of the common confusion in socialism is that the 'State' is paying. Who is this State? Where is this money that the State uses to pay the medical bill of the society coming from? It is like you are saying that in capitalism, the insurance company is paying for health care services. This is not true. People are paying for, not the state, not the insurance company. Every month people are paying consciously their taxes, insurances and so on and that money is used to pay the medical bill of the society.

What consequences come from this? First is the confusion between State and God. The State becomes an almighty God who decides who receive and who does not: *The Lord gave and the Lord has taken away*[12].

Anyway there is another consequence, we tend to consume more services if we have already paid for it. It happens not only in the medical field, but also in everywhere else in the public sector. And of course we are 'helped' to learn that we need more and more of those services. In the medical field people 'learn' about the miracle of modern science from media and they end up wishing those miracles, even though they do not really need them, even though they are not really miracles. It is the difference between Swedish buffet and menu a la cart. The first one is a little bit cheaper, has more quantity and less quality, but it will still make you feel better because you receive something that you did not really want, nor need it in the first place.

The third consequence, in my opinion is that competition is not stimulated, effectiveness is not really a concern. In order to exemplify this I will quote from Jan Roth Johnsen report: "The analysis of the relationship between efficiency and financing (Biørn et al 2002) showed that the introduction of activity-based funding in 1997 resulted in immediate increased technical efficiency, but at the same time increased total costs. The interpretation is that the activity-based funding resulted in larger growth in activity than in resource achievement, so this growth was expensive. The hospitals had little knowledge about their own costs, and together with soft budget frameworks this resulted in a strong and partly unexpected growth (Slåttebrekk and Aarseth 2003)."[13]

[12] Bible, Bok of Job, 1:20, New International Version, ©2011, http://www.biblegateway.com/passage/?search =Job+1&version=NIV

[13] Idem 1, pg 150-151

In my opinion, no further comments on this issue are necessary.

How we increase individual responsibility, this is indeed a challenge in any socialist system.

In the Norwegian health services has been introduced the out-of-pocket system. I guess it make people think twice before they visit their doctors and evaluate thorough whether they need medical services or not. In addition, since 2008, there were created 32 guides and regulations regarding patient's access to the health services which supposedly will create an equitable system and it will decongest it.

Yet it does not stop here. More and more people agreeing with the inequality in health services. In the Norwegian newscast on 7th March 2011 (Dagsrevyen 21. Nyhetsmagasin med Norge i dag og sport) at the national television NRK1, the following news was presented: "People who smoke, drink or disregard medical advices of their doctors, should be lower prioritized in obtaining medical services."[14] We find out then that according to a study conducted at the University of Oslo, about 45% of the Norwegian doctors are willing to discuss about the importance of self-responsibility in the process of prioritizing patient. Why should medical doctors discuss about this, why not the general public? In this moment, the patient's access to medical services is evaluated according to three criteria: the diagnostic's prognosis; the ability of the patient to benefit from the treatment; the costs of the treatment.

Although I understand the dilemma 'so many people, so little money' and as I said before I admit that we, people, all of us have a tendency to consume more than we can create, afford and even more than we need, I have trouble to accept the moral legitimacy behind playing with other people's lives.

It might sound reasonable for example to take under consideration the price of the treatment, but how much is too much when it comes to human life? What if we are talking about our own life? Can we accept that there is a treatment, but it is too expensive? I remember I once read a very wise quotation of Albert Einstein: *Not everything that can be counted counts, and not everything that counts can be counted.*
Besides, if you do not consider yourself a robot, you realize that the evaluation of a patient's ability to benefit from a particular treatment in a particular situation is a very subjective process.

[14] http://www.nrk.no/nett-tv/klipp/719039/, see also appendix 2

First, you as a person do not have the capacity to understand all the dimensions of that patient case. Second, you might not like the patient, she might remind you of your ex-wife, he might remind you of your awful neighbour, or he might be your awful neighbour. Third, the statistics behind that particular treatment will never reflect the situation in the reality. Fourth, people have different life's experiences, different motivations, different particular characteristics and they will most probably react differently to the same treatment. Fifth, miracles do happen. Sixth, I have to admit that there might be some other things my mind could not think of.

Anyway, the worst part is yet to come because we leave behind the general provisions of the law and enter into specific issues of social aspects. I am referring now to the research presented in the newscast on national television. In conformity with the research findings, we may say that about 45% of Norwegian medical doctors are willing to discriminate between patients based on their habits. A general practitioner comment upon this issue that he, and others wishes to have the possibility to demand 'more' from their patients.[15]

This sounds wrong, if not out of any other reason, then because in the today society we talk so much about tolerance and integration of all individuals regardless sex, age, political view, religion. The whole society, smokers and non-smokers, drinkers and non-drinkers all pay for social houses and medical treatment for those who are addicted to illegal drugs and yet we consider discriminating people because they smoke and drink.

Besides, how would they manage this? How would you know if a person drinks one glass of wine or 10? If they walk in the park or just drive through the woods? If they smoke or it just happen that they have fireplace in the house? Should we develop electronic devices to follow them up?

Last but not least, what is the limit? Where should we stop? How about sexual behaviour? We know that people who are unfaithful to their partners are exposed to a higher risk of sexual diseases. Should they be prioritized? How about aggressive behaviour? We also know that aggressive people end up often in fights and therefore have a higher risk of accidents. Should the society pay for their medical bill? I honestly believe that this campaign for healthier individuals looks more like a witch-hunt in medieval times.

[15] Idem 14

CHAPTER FOUR

THEORIES ON EQUALITY, EQUITY AND JUSTICE

Here it is the first ethical principle that is stated by the American Medical Association: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights"[1]

Unfortunately, "competent medical care" is depending on resources and when scarcity of resources occurs, we should decide who receives the competent medical care and when and even how "competent" medical care.

Despite huge investments in health, at least in OECD countries, we still struggle to manage all the cases that need medical care.

At the individual level, physicians apply the rule of thumb: they will treat as many patients as they can care in order to guarantee high quality. This rule satisfies the criteria for common sense. When we have to go further, above the personal rationing, more elaborate rules and principles are required.

More or less open, the *social worth* criteria applies for other kinds of rationing as for instance in hospitals. Decision makers tried to judge the social worth of a patient by anticipating the contributions of a particular patient to the society. Not only that this type of discrimination is not ethical, but it is not possible to know and measure the contribution of a person. An industrial employee is as important to the society as a university professor is; the first might not earn as much money as the second, and the first profession might not be as prestigious as the second, but for the well being of the society both are very important and therefore have same value to the society.

[1] http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page

The *social worth* principle in practice has as result increasing the gap between different categories of people in the sense that *popular people* will always be preferred over *the unpopular*, or *school graduates* over *the uneducated*¸ *good, devoted people* over *the unfaithful* and so on. Somehow, we have a tendency to perpetuate the same *old values* and there is nothing wrong with that as long as we do not send people to death sentence based on these values.

Another principle is the *lottery* criteria based on which the first patient in line is the first one to be served. This is in a way, the rule of thumb in the macro system. Many bioethics argue that the lottery criterion is both ethical and equitable. The problem is that this principle works better in theory than in practice. As health personnel, people have a duty to give assistance to a person in a critical state of health. And this rule is higher than any other. That is why the hazard cannot rule the health as long as the patient is in the presence of medical personnel.

There is one exception from the humanitarian rule and this is the crisis situation either the war or natural disaster where the general public welfare is in question. In those cases, the utilitarian rules upon the humanitarian even at the risk of death. Even though this military triage is not justified in peace situation, there are more and more economists that talk about it in health services.

Finn Diderichsen argued in his discussion paper upon Health, Nutrition and Population that "For administrative reasons, resources are usually allocated as they always have been – which relates more closely to the existing structure and demand than to need."[2]

There is, according to Finn Diderichsen, a clear distinction between *need* and *demand* in the sense that the demand oversize the need. As a psychologist, I know that society as a system has the means to regulate its self. If we see away from the health issue for a while and question what is happening in security related issues we will find out that indeed, some people will rapport fake incidents and will demand unrealistic compensation. On the other hand, the people who do not rapport incidents, and suffer therefore injustice, and receive no compensation what so ever are at least as many as those in the first category. From a macro perspective, that evaluates the balance in the social interactions, this ability of a society to auto regulate is a natural way the solve problems. Yet, from philosophical perspective, this *auto* regulation raises some ethical issues. Unfortunately, it is impossible to identify in real

[2] http://siteresources.worldbank.org/HEALTHNUTRITIONANDPOPULATION/Resources/281627-1095698140167/Chap8DiderichsenRAforHlthEqtyFinal.pdf

world and in real time whom needs indeed help – no matter what kind of help – and whom is demanding unjustified help. Yet, we try and we call this *resource allocation policy*.

When we talk about resource allocation in health, we need to have in mind that there are different levels of allocations of resources in a society.

First, decision makers are allocating resources among competing groups of people and/or programs. Let us say that the budget should be divided between social services, health and economical development. One possible decision would be to divide the resources equally between all three programs or to allocate all the resources to a single program. The decision makers face here a serious dilemma: what is more important at this moment for the entire population – health, social protection or economy?

If we assume that the health program receives a slice from this pie of resources than we go to the next level of allocation of resources, which is regarding allocating of resources within the health services and here the debate is focusing on the value of each health program – how important it is to have for example public educational programs that promotes healthy lifestyles and prevent epidemics? If it turns out that such health educational program is important and has great benefits for society than the program will be financed. After that, we face the problem of allocating the resources at the individual level.

Those two levels of allocation are not issues of discussion in this paper. The last level of allocation is the main theme of this paper since is referring to allocation of resources among individual patients. Decisions at this level that can make the difference between life and death some times, are taking based on one or another theory of justice depending on what social policy is most popular in a particular time (Rawls, 1971).

Before we go further into the theoretical dimensions, it has to be said that all those theories are based on a single assumption, *the moral good principle*. The common link between all the ideas that were generated from the beginnings of social philosophy is without a doubt *the moral good*, the question is whose good we refer to – the society, the nation, the individual, the working class or what?

Let us present some of the most known and debated ideas during the last centuries all over the world. (Rawls, 1971; Olsen 2009)

The general conception. With respect to justice, the general conception is that all social primary goods, such as liberty, wealth, self-respect and so on should be distributed equally among equal individuals. Unequal preconditions should conduct to distribution of primary

goods in the advantage of the least favored. But how to measure *the least favored*, and how to recognize *the least favored* among those that claim to be *the least favored*.

The social contract. Free people need to agree on some ground rules in order to live together in harmony. This idea is so simple and so according to the moral good principle that is almost easy to oversee an important distinction that the theory is making, that there are two categories of people – free and slaves. If we assume that in today's world, there are no more slaves than we can also see the benefit of the contract. I suppose that such social contract have been established at the declaration of human rights. However, the contract did not stop the exploitation of human being by other human beings, and does not improve the situation in health sector.

The utilitarianism theory or the greatest happiness principle. The main rule is to seek the greatest good (maximize the pleasure and minimize the pain) for the greatest number of people and the best action is choose depending on the action's effects or consequences for you and others. At the abstract level, the theory makes sense and most individuals are willing to sacrifice, up to a certain point, their own good for the sake of other. Life provides numerous examples in the favor of this theory, but unfortunately proved also that the utilitarianism theory can easily be abused as it is the case in the fascism ideology.

The egalitarianism theory. A society created based on this principle makes sure that each member of the community receives a equal share of unit that it is to be distribute in the same way to everybody regardless prior conditions.

The quality of life principle. From health perspective, all of those theories make sense and yet are useless in the same time. Words like equality and equity raise compliance among people, but what actually do they mean? *Equal* with what? *Equity* in rapport with what? Should we assure *equal* start conditions to everybody? After that every person is left to deal with life alone? *Equal* effect? *Equal* prospective health as the social contract principle suggests? *Equal* expected lifetime health as egalitarianism theory suggests? *Equal* gains as utilitarianism theory suggests?

Trying to answer those questions economists come with a solution – find a basic, common and practical definition, that it is simple enough to calculate and demonstrate, that is complex enough to incorporate all the dimensions that matters and besides that is universal.

The solution has the name of *quality of life* and it turns out that it is not that simple, nor basic, nor universal as it was hoped to be, but rather complicated, partial and controversial

theoretical concept used more to justify discrimination in health services than to help people to access health care as easy and fairly as possible.

Yet, when the system is affected by scarcity of resources, the question of whether or not to pursue extensive medical intervention on a patient appears to be more and more referring to this dimension: *quality of life*. There are several problems related to this concept. One would be who is deciding the quality of patient's life – the medical doctor, the patient's family or the patients self. Different studies like "Who should measure quality of life, the doctor or the patient?"[3] questioned the doctors ability on that matter. There is a significant difference between the quality of life of the patient when is made by the doctor and when is made by the patient self. Besides, it seems a little bit unfair that anybody else but the patient or the patient's family when is necessary is doing this kind of evaluation. At least, the patient should be involved in such evaluation.

The second problem related to the quality of life is how such evaluations been made and based on which criteria should they been made: age, ethnicity, mental health, personally characteristics, ability to make good decision, other medical conditions, sexual practice, social and economical status etc.

Third, which life do we refer to? The quality of life on Earth? The quality of life before the sickness? The quality life of the perfect individual – free of all symptoms? The quality of life after the symptoms occur? After the first symptom? After all the symptoms? The quality of life gain during the treatment? After the treatment? Immediately after the treatment? A year after the treatment? How about in the case of those disease that affect the mind or/and the ability of the person to express his- herself? Should we ask the family? Should we ask the general public in case that the family is not available or is not well intentioned? Should we ask specialists?

How does the quality of life principle influence the health care services actually? Well, in order to manage the demand in health care you need to have a reason to control the access and measurement of the quality of life becomes an instrument for control.

The simple methods used to measure the quality of life was VAS or The Visual Analogue Scale where a person evaluates own health on a scale from zero (the worst imaginable state of health) to 100 (the best imaginable state of health).

[3] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2246701/pdf/brjcancer00135-0117.pdf

Some health researchers argue that the risk of the treatment should be the criteria for evaluating a medical intervention. This method is called The Standard Gamble Utility and is evaluating how much risk during medical intervention a person is willing to accept in order to be cured from symptoms. In other words, knowing that the intervention has X% chances of failure a person is asked to evaluate whether or not the symptoms worth the risk.

Another method is TO or The Trade Off formula and here we are talking about The Time Trade Off and The Person Trade Off.

TTO or The Time Trade Off method is asking people to imagine life free of symptoms and life with the symptoms and then they should bargain years of own healthy life in order to compensate for the discomfort caused by the symptoms. For example, the person should choose a preference between let us say 10 years with symptoms or X year free of these symptoms (where $X < 10$).

PTO or The Person Trade Off method is more absurd than I personally ever imagined to be faced with. Anyway the idea is that a person should bargain between saving a life of one person and prevent X cases of a particular illness. The question is how big the X has to be in order to justify killing one person. I guess it is possible to formulate this method less dramatically than I did, but I do not to hide the facts behind fancy words.

Somehow these methods fail to satisfy the demand for a valid and complex instrument in the prioritizing process. A multidimensional measurements was requested and a QALY was the answer. A QALY or Quality Adjusted Life Year is the arithmetic product of life expectancy and a measure of the quality of the remaining life years. A QALY provides a framework for valuing the health gains associated with interventions combining the estimates of both the extra length of life gained and the quality of extra life gained. Unfortunately, it is both controversial, difficult to calculate, oversimplifying the health care issue and ignoring sensitive aspects within good / ill health.

Years of studies proved nothing yet more and more researches are developed and implicit more and more money are spent in order to find out how to choose the best of worst.

An example in this sense is *A Discrete Choice of Exercise* that was conducted at the Institute for Health Economics and Management – University of Oslo in 2010. My colleagues and I were asked to imagine ourselves as decision makers in a medical unit and face the problem of choosing one out of two patients and there were 14 such pairs of patients. I remember to experience discomfort while riding the exercise, in my opinion absurd, and I was not able to

participate since I could not understand the point or the scope of such questions. (see appendix 3)

Theory after theory have been elaborated to formulate criteria and examine the arguments for equality and equity, fair and just and the right to health. At present, agreement does not exist on any of these issues. It is stated everywhere in bioethics that all persons should have access to *minimum* of health care necessary to sustain life, prevent illness, relieve distress and disability. Yet some of us have different opinion about what *minimum* of health care means and reality remembers us to consider the time perspective in this equation. Force the patient to wait in line for a long time to obtain that *minimum* of health care might mean the difference between sustain life and declare the death.

Health care is a special good in the today society that should be allocated to reduce if not eliminate the impact of bad preconditions, to ensure that everyone has the same access to what they morally deserve and basically to establish fair equality of opportunities.

Since this definition looks a lot alike utopia for health care services, health economists come with a good deal of plans, formula and not least theories that should regulate the need and control the demand for health care. The result is a disaster, as we can learn mostly from the media but not only.

In my opinion, a better health policy should focus mainly on how to increase effectiveness in health sector, how to help people to help themselves before they need a doctor and much less on how to regulate access to health care.

CHAPTER FOUR

DESIGN AND METHODOLOGY

This paper is based on two different perspectives. First, I was looking to understand the decision-makers, and here I attempt to find out what kind of problems do they face and their struggle to do a great job. For this a semi-structured interview was design and it has been evaluated the quality of referral from family doctors. Although everybody is agreeing that nobody should wait for treatment, there were significant differences when it comes to reason and justify the waiting list.

The semi-structured interview follows the decision makers way of thinking and reasoning with respect to prioritizing of patients; how do they make their decisions and how do they justify their decisions? In addition, the interview tries to capture possible problems that might occur in the process of selecting the right solution for the right person. The interviews were conducted with two decision makers from Ullevål hospital and one from Ahus hospital – they wish to remain anonym and the original interview in the Norwegian language can be found as appendix (see appendix 4).

The dimensions of the interview

I. The first dimension measure the personal view on the matter, and there were asked questions like: *what is your opinion about prioritizing patients? do you consider it necessary? fair? ethical?* There are three questions in the beginning of the interview and one last question at the end of the interview. This last question follows an important theme in the interview (see the forth dimension). This question is more philosophical than practical and the aim is not only to find out how they think but also to make them aware about the possible danger of process: *how do you justify the difference between the one who decide and the one that gets left behind by the system in a world were supposedly everybody is born equal? in other*

words, how do you justify your prerogative to decide upon another person life? what philosophies back-up the prioritizing process?

II. The second dimension put under discussion *how do they take the decision, what they need in order to take the right decision and how difficult it is to take such decision.* I also open for discussions with respect to other areas in medical field or other process in patient treatment, such us deciding a psychiatric diagnosis.

III. This dimension is the most practical one since the questions refer to the statistical information on how many patients are waiting for treatment, and for how long.

V. The last dimension is quite different from the other four because is asking the subjects to do some imagination exercises. In the first exercise, they should try to imagine what kind of consequences 12 weeks waiting time can have on a child with psychiatric symptoms. In the second exercise, they should try to imagine themselves as patients and question themselves: *what if it is you who needs treatment as a patient? are you willing to sacrifice your health to the benefit of others? how many days would you be willing to wait for treatment? and how sick you will have to be in order to be the first in line? to be prioritized? which health effect has so low significance for you that you would not consider worth following the treatment? one year? half of year? or less? which cost would you consider to be too high for society to pay for your health?*

The Children Psychiatric Clinic in Hamar is currently part of two running projects. The first project has as aim to improve the quality of referral from the family doctors to the psychiatric health services. In the stage one, 2010, a number of 54 referral from family doctors were evaluated on a scale from 1 to 24, where the 24 points represent information about the patients which should exist in the referral. In the second stage, the family doctors were informed about the results and the most important and most problematic aspects with the referral were discussed. The third stage, 2011, other 54 referrals from family doctors were evaluated with the hope that the quality will be improved. The project is continuing since the situation was not significant improved.

Referrals to psychiatric clinic should be evaluated in conformity with the prioritizing guideline: ”Psychic Health for Children and Youth”. It is extremely important that the referral contain all the necessary information in order to be able to evaluate correctly and soon enough and to prioritize fair those who need medical help in psychiatric units. The referral were

therefore evaluate on a scale from 1 to 24 in order to obtain information on six dimensions (see appendix 5).

I. Patient's personal information like name, parent's name, other siblings, address and the child or the parents consent to treatment.

II Reason to referral where the family doctor has to do his/hers evaluation of the patient.

III. Social status and other secondary yet important background information such as learning difficulties, mobbing, social burden, violence, poverty, alcohol consumption, is there any other member of the family suffering from a medical condition, or other issues that might influence the situation.

IV. Symptoms described by the child self (the oldest the child, the more important is self describing the symptoms) or observed by the primary care doctor during the examination, by parents and family at home, in the free time or by school/ SFO/ kindergarten. Here it is also important if the referral offers information about what is the patient's motivation for the treatment, what kind of help it is wanted and related to which issues.

V. Somatic status of the patient.

VI. Other interventions now or previous to this episode. Here should the family doctors give any relevant information such as: has the child previously been referred to a psychiatric clinic? has the child received psychiatric treatment? is there any other instance involved in the case now or before?

In the second perspective, I tried to find out how "great" is indeed their job; and since there are the patients, who pay the consequences if the decision is not fare to them, it seems logical to name this perspective "the patient perspective".

In this part of the paper I presented five referrals to the psychiatric clinic which in my opinion are quite representative for The Hamar Children Psychiatric Clinic. In addition, I did also a presentation of the second project.

The second project is attempting to find out how different decision makers evaluate same referral. In this stage of the project 20 referrals have been evaluated by six different team of decision makers from six different psychiatric clinics. The results will show if the decisions are sensitive or not to the influence of the human factor.

CHAPTER FIVE

FINDINGS AND INTERPRETATION

Before I go further with presentation of results, I want to make sure that, whoever reads this paper is aware about the purpose of it. I wrote in the foreword that I do not aim either to solve the problem or to hold responsible anybody for any shortcut the system shows, but to raise ethical questions and to increase awareness among those that are involved or interested in the issue. Maybe this is the reason why my paper do not follow the general rules of presentation of a master thesis or maybe it is just my nature that stands against the norm. Anyway, you will find the paper out of the ordinary on a number of levels. One might argue that it does not follow the chronological line, or that the interviews are not interpret but presented as a report, or that the context is not well enough defined. Yes, you all have right, but that was my intention. I do not want to write a paper were the context overshadows the particular element.

Edvard Munch was criticized at the first exhibition because in the critics' opinion, the paintings were unfinished. I am not comparing myself with Munch, but I really like his answer to his critics: "It is better to paint a good unfinished painting than a bad finished one. Many people think that a panting is done when they have put into it as many details as possible. A stroke of a brush can be for that matter a finished piece of art. When you paint, you have to do it with will and feelings. (…) A painting must not be fake and senseless and it cannot be that as long as it was done with feelings and awareness."[1]

I do believe that we should write more with awareness and feelings than with the determination to follow a standard line. I do not want to fit my paper into those lines; I do not want to express the general opinion; my paper is not perfect and it was not intend to be so; my paper is not a piece of art either, is just a simple expression of human subjectively experience of mental health system.

[1]Lunde SE., *Biografien om E. Munch. Livets dans,* Gyldendal Norsk Forlag AS 2oo4, side 112; This is my translation and not a professional translation of the original text

1. The Decision Makers Perspective

1.1. The interviews with the decision makers.

Interview 1 – Ullevål hospital

Understanding the process

- pluses and minuses

This is a very important issue, in my opinion because this group of patients is very weak and they cannot speak loud and clear for their rights and needs. I am depending on family and social connection in order to reach and understand the patient situation and I do consider it an ethical issue when we reject a patient because we do not have enough capacity… further more if they do not receive other medical services from another institution.

- how difficult it is to do such analysis and to decide which patient can wait and which one cannot?

It is indeed very difficult, especially if you compare it with somatic field; if you have a broken arm and a twisted ankle, you know that you have to prioritize the broken arm and that the twisted ankle can wait. Psychiatry is less clear, I mean we do not really know what do happened in that person's life, what kind of social aspects influence the state of health; and it is less objective, it up to me how I evaluate the patient, another doctor might see it differently; a broken arm is a broken arm for everybody, a depression is not just an indices in a table, it might be moderate in my eyes and severe for anyone else or vice versa.

- also, how fair it is?

And that is why it is not fair, not only that nobody should wait for treatment, but it can easily happen that the 'wrong' person is ending up at the end of the list.

The team

- who make the decision and based on what?

We are 8 (eight) in the team, 7(seven) psychiatrists, one from each department and one coordinator and we meet twice a month and we evaluate all new cases. We try to find which offer is best for every patient.

- experience in the medical field

Experience should one have as much and as wide as possible. Psychiatry is not like commerce, you do not buy nor sell, is not like repairing a carpet, you do not cut and replace the destroyed part and it is not magic either, you do not say hocus-pocus to fix the patient. You have to find out what the patient needs, what is the conjuncture, what can help and if we can help, how can we do it in our department.

You have to understand that these guidelines for prioritizing of patients in mental health are not for us; we cannot use them. Here in our department we do not have a "suspicion of depression"; we have a history, a file that proves that. The patient comes with this file from the psychiatric clinic, where they tried to help and they failed. That is why it has to be mandatory that every patient receive treatment immediately in one of our departments. However, I cannot say that we succeed every time.

- the degree of satisfaction with this particular job assignment

When we cannot succeed, then I am not satisfied! Of course!

The statistics regarding the waiting time in that particular station

- if there is any information on this matter and how accurate there are?

As far as I know there are no such data, and there should be, in my opinion.

- in reality, what do happened with patients while they are waiting for treatment?

I believe that it is irresponsible to let patients with severe psychiatric syndromes waiting for treatment. We know, if not from anywhere else, than from literature in the psychiatric field that prognosis goes from bad to worse without treatment. While they wait, the problems are rarely disappearing.

The view on prioritizing from a personal perspective

- what if you are the one that needs medical care? how much would you be willing to sacrifice for the benefit of the society?

No, I am not so sure that I am willing to sacrifice my health for the benefit of the society, but I can wait for treatment in certain conditions. I can wait if my functional capacity is reduced, but I cannot wait if I have pain. Psychic pain… (no answer)

- how much should society pay for medical services necessary to improve your health?

It costs society relatively much if I get sick…

The ethical dimension of the prioritizing

- how ethical it is to let patients to wait for medical treatment?

Well, it is not! It is not ethical to let patient to wait for treatment and it is definitely not ethical to let certain patients without any medical treatment because I am actually worry for those that do not contact medical services because they do not know that they can or that are not referred further to a specialist by their family doctors. We know that there are such cases, people that are suffering quietly, alone, with no hope and no chance to receive treatment.

Interpretation of the first interview. It is not fair, it is not ethical to let patients to wait for treatment, is the conclusion at the end of this first interview. This person is really struggling to cope with the pressure of making the right choice, the right decision. I cannot help wonder what is the price to pay for this kind of effort. Is there any decision maker in the managerial team measuring this psychological pain caused by the unnecessary pressure when calculating the gain of society by prioritizing? It is like asking parents to choose between their children: I will give bread to the first-born today and the second tomorrow; the third one must wait until next week.

Having a strong feeling that this person is really doing the best job possible considering given circumstances, I wish this person all the best.

Interview 2 – Ahus sykehus

Understanding the process

- pluses and minuses;

It is necessary. If you think about it you realize that it is necessary, because there are not enough resources for everything and because you have to think that these patients that are already in treatment need to finish their programs. If new-patients receive a place immediately, old-patients have to leave earlier, and that is not good for anybody.. Nobody should have to wait, unfortunately we have a limited number of stations, we have a limited number of personal and we work a limited number of hours.

- how difficult it is to do such analysis and to decide which patient can wait and which one cannot?

It is difficult but I have trust in myself and in people I am working with that we doing a good job, or at least the best we can.

- also, how fair it is?

It becomes fair to prioritize between patients only if you think of the patients as a group – the group of patients that are treated in our clinic, on the whole have the best offer possible; they might have to wait few weeks in order to begin the treatment, but once they started they are not force to leave it before the right time, just because another patient has arrived.

The team

- who make the decision and based on what?

There is a team of 4(four) that make the evaluation of the patients and I am, as manager of the clinic, the coordinator of the team. The process has to stages: journal evaluation and meeting the patient. The journal comes from the family doctor and it is comprehensive when the doctor knows the circumstances of the case, and the family, and the history of the family and so on. If not, than the journal is not that useful. As soon as possible, but not later than 10(ten) days we appoint a meeting in order to understand better what is the situation, what type of needs the patient and the family have, how severe the symptoms are. If the patient has to wait, we try to give as much information and advices as possible, and we give a good deal

of advices to the patient and the family on how they should approach a new event if necessary.

- experience in the medical field

I believe that the experience and common sense are very important in evaluation of the cases.

- the degree of satisfaction with this particular job assignment

I am quite satisfied otherwise I would have done something else, is it not?! But I feel that it can be better, that the situation could be improved. Any way it has to be said that it is better now than it was before the apparition of the guide for prioritizing in mental health. Before those guidelines, it was 'normal' to wait for treatment half of year, which I believe to be unacceptable and irresponsible.

The statistics regarding the waiting time in that particular station

- if there is any information on this matter and how accurate there are?

I can give for example some numbers from February last year: our clinic had in treatment approximately 400 patients, there were 23 patients on waiting list and they were waiting 44 days in average. We make such statistics all the time.

- in reality, what do happened with patients while they are waiting for treatment?

There are always some cases that become so severe and family calls to say that the situation is worst and worst and that they need help. On the other hand, if they do not call, when they come to start the treatment we ask them what did happened while they were waiting and we find out that they did not experience it very well. And probably not everybody who have complains talk about them, people are polite, and kind, and pleasing, and prefer to forget the worst in the past and focus on the positive future.

The view on prioritizing from a personal perspective

- what if you are the one that needs medical care?

It is not so easy to evaluate your own case, what does it means to have a reduce capacity, in what conditions… I understand what your point is, that nobody should wait!

- how much should society pay for medical services necessary to improve your health?

No answer.

The ethical dimension of the prioritizing

- how ethical it is to let patients to wait for medical treatment?

I do not believe that we, I and my colleagues should take the responsibility to answer this question. I think that the government, the health minister, the health department and so on should debate on this. I know for sure that everybody that works here are very responsible in their work. It will be wrong to ask us this question. It is somebody else that decides how many resources we can use. It is not our responsibility alone.

- also, is it worth it? does the society really gain from it? do we, as a society really save money like this?

I do not believe that we have ever evaluated the cost-effectiveness of a treatment regarding a specific patient. I know that is saying so in the guideline, that it has been suggested three criteria, and cost is one of these, but I do not believe that we, here in this clinic ever did that.

Interpretation of the second interview. After talking with this person, I have a feeling that somehow the situation is not that bad. I guess is one of those situations when statistics make wonders with human brain. If 400 patients receive treatment and 23 were waiting in average 44 days, somehow it makes it right. It cannot be perfect. Everybody experiences sooner or later unfair treatment in the public services, respectively health services, no matter how hard we try. It does not make it right, and it is not fair for those 23 and it causes definitely psychological pain to see them suffering, to realize that they could have been treated sooner. But again, somehow those 400 patents in treatment reduce the pain.

In addition, I have to admit that I receive the best justification I can think of for the situation: *If new-patients receive a place immediately, old-patients have to leave earlier, and that is not good for anybody.*

I am also impressed by the fact that in this is institutions the decision includes the patient and the family. I hope that this kind of practice becomes mandatory in all health units that have to

prioritize between their patients. I believe it is a good practice to hear actually from the patient how he or she experiences the situation and not make decisions based only on papers. Not least, it has to be said that it shows deep consideration for patient suffering when they give advices about how the patient and the family should cope with the situation while the waiting for treatment.

Best of luck further in your work!

Interview 3 – Ullevål hospital

Understanding the process

- pluses and minuses;

I would say that the system works well. I know that some systems demand particular information in order to start the process, but in our center we invite people to a discussion in order to clarify the situation, which discussion helps also – people learn what they can do while they are waiting, or in the case that they will not receive help here.

- how difficult it is to do such analysis and to decide which patient can wait and which one cannot?

It is how it is. Sometimes is easier, sometimes is harder. Usually we have a lot of information from the policlinic, the patient journal, tests, evaluation. But if the crisis has just begun, we do not have enough to based our judgment on and yet we cannot wait with the decision until the evaluation from the policlinic has come. Any way if I consider that the patient journal is to weak than I send it back and them, the policlinic to do this, and this, and this…

- also, how fair it is?

It is neither fair nor unfair. Fair is an irrelevant word. This has nothing to do with fairness. This is a wrong question; it does not fit into picture. When you think what happened in Japan lately, was it fair? No, it was not. It is life and nothing to do about it.

- In my opinion there is a difference between a natural disaster and prioritizing

Yes it is. But then again you do not have money to treat everybody, what you gone do? You can try the line order – first one in line is first one in treatment. This is a type of fairness, but it does not evaluate life's danger. We try to prioritize the one who has is worst.

The team

- who make the decision and based on what?

We are a team here at the hospital, from all the departments, and we discuss each new case that was referred from the policlinics. We decide which cases are supposed to be admitted in our departments and which should continue treatment in the policlinic. In the end, we decide which department is appropriate for which patient.

We are depending on patient's journal, but not only.

- experience in the medical field

Experience is the most important factor in order to decide who is needing help first, what type of help or when.

- the degree of satisfaction with this particular job assignment

No answer.

The statistics regarding the waiting time in that particular station

- if there is any information on this matter and how accurate there are?

At any moment there is 4 to 7 children who are waiting for help from our center – they were refer from policlinic and we "admit" them but we do not have the capacity to treat them immediately. Before Christmas were 6 children waiting and now they are 5. They usually wait 3 to 5 months. If the family is calling to say that it happens this and this and this, that child can come further in the waiting list and the period reduces to 2 months. And if the situation is so acute the child will not wait more than half of month. In the same time, some children wait even longer. Right now, we have a patient on the waiting list since November and we said first that we would be able to admit the patient in March, which means 4 months waiting time, but we received other cases in the mean time, that could not wait and the patient will have to wait until May, which means 6 months.

- in reality, what do happened with patients while they are waiting for treatment?

Some patients become well or at least better then before, regain some control on their health even though they are waiting. This happens because the idea that you will get treatment eventually helps a lot. The sickness, just like life and anything else goes in periods; good times alternate with bad times. The patient contacts the health care services when he or she is in the bottom of the curve, under the "good-enough" line; they keep fighting and fighting with the symptoms, until they cannot fight anymore so they become desperate and call the doctor. By the time they meet the doctor, they are already on the way up. Of course, the most critical conditions can go from ill till worst!

The view on prioritizing from a personal perspective

- what if you are the one that needs medical care? how much would you be willing to sacrifice for the benefit of the society?

There are two situations here. If we talking about a condition that it does not affect my living, let's say a knee operation, then I can wait three months, I can then read everything otherwise I do not have time to read. But if we are talking about anxiety which needs treatment immediately and the prognostic is bad without treatment, in this case I am not willing to wait at all!

- how much should society pay for medical services necessary to improve your health?

Again, it depends on the situation.

The ethical dimension of the prioritizing

- how ethical it is to let patients to wait for medical treatment?

You cannot ask question about ethic with respect to prioritizing. Again, it is neither fair nor unfair. It is nothing at all. The world is not complete; the world is not fair; life is always random and unfair. It is the society and financial power of that society that decide after all who is getting treatment and who is not; there are somebody who decide how a particular society will use common finance – shall they be used to construct streets and bridges or shall they be used to treat people. Somebody do these decisions; I can agree or disagree. Because I work with children, I want the society's money to be used for treatment of children. Either this

or that – quite random. It depends on who is making the evaluation of the system, the society, the policy and so on. I just want to help those who need most and biggest help.

- also, is it worth it? does the society really gain from it? do we, as a society really save money like this?

I think that is a good economic policy to let them not to wait. If somebody had asked me, I would recommend prioritizing of children's treatment more, much more than today's policy. The help that a child does not get today, before the child is growing into an adult is going to cost society a lot more for at least 50 years ahead. So yes, if somebody would ask me, I would prioritize health services for children even stronger.

Interpretation of the third interview. It is easy to understand why people get into denial process while they have to face this type of work. In this interview becomes obviously the effect of long-term exposure to prioritizing process: detachment of feelings from the work related issue. It is not that the person does not care, or does not have an opinion on prioritizing process. It is that the person can no longer tolerate the question. It is a defense mechanism that has been activated in order to protect oneself against own actions.

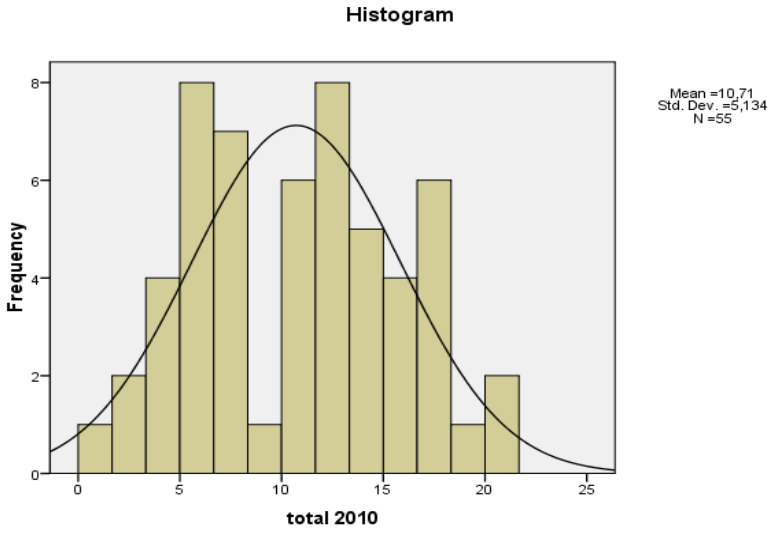
Questions like *who am I to decide, or have I made the right choice* are covert by a bigger event, in this case the earthquake in Japan. But even though in this person's opinion fairness is not a *real* question, I see that exist a *real* concern for those patients that have to wait.

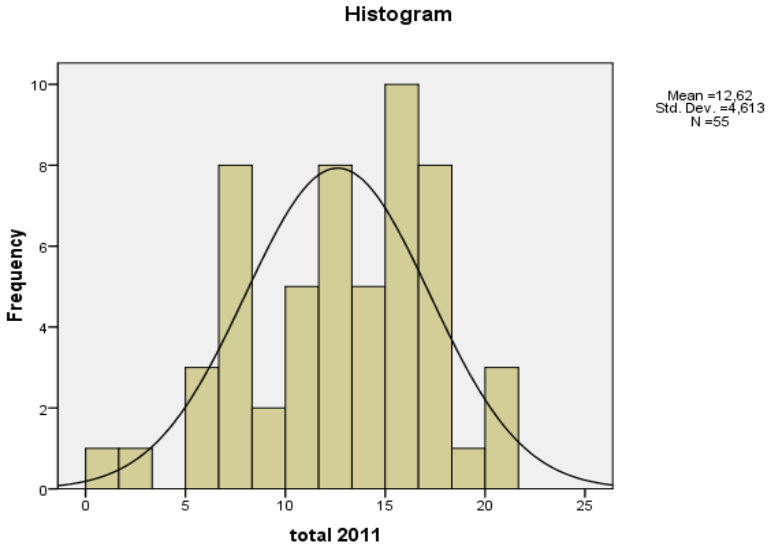
I wish this person also all the best, being sure that this person is also doing the best job possible considering given circumstances.

1.2. The First Project – The Evaluation of Referrals from Family Doctors

The referrals from family doctors were evaluated on a scale from 1 to 24 in order to obtain information on six dimensions (see appendix 5). Here are the results for Hamar Psychiatric Clinic for Children (BUP Hamar) from 2010 and 2011.

Total Score for 2010 and 2011





Ranks

	GRUP	N	Mean Rank	Sum of Ranks
TOTAL	DR 2010	55	49,08	2699,50
	DR 2011	55	61,92	3405,50
	Total	110		

Test Statistics[a]

	TOTAL
Mann-Whitney U	1159,500
Wilcoxon W	2699,500
Z	-2,115
Asymp. Sig. (2-tailed)	,034

a. Grouping Variable: GRUP

- The Mann-Whitney coefficient for heterogeneous groups shows no significant difference between groups.
- The media was 10,71 in 2010 and 12,62 in 2011 out of 24 total point sum; I guess we can say without a doubt that is definitively place to improve the performance. But I consider important to see how those point are distributed between the six dimensions.

Personal Information Score for 2010 and 2011

Group Statistics

	GRUP	N	Mean	Std. Deviation	Std. Error Mean
Personal info	DR 2010	55	3,49	,858	,116
	DR 2011	55	3,65	,751	,101

Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means				
						95% Confidence	
Personal info	F	Sig.	t	df	Sig. (2-tailed)	Lower	Upper
Equal variance assumed	2,530	,115	-1,065	108	,289	-,468	,141
Equal variance not assumed			-1,065	106,133	,290	-,468	,141

- The independent sample test for homogeneous data as it is the case on this dimension shows no significant differences between is again not significant.
- The family doctors scored best in both years on the first set of items – personal information with a media of 3,49 for 2010 and 3,65 for 2011 out of 4 maximal points.

Reason to Referral Score for 2010 and 2011

Ranks

	GRUP	N	Mean Rank	Sum of Ranks
Reason to referral	DR 2010	55	48,43	2663,50
	DR 2011	55	62,57	3441,50
	Total	110		

Test Statistics[a]

	reason
Mann-Whitney U	1123,500
Wilcoxon W	2663,500
Z	-2,386
Asymp. Sig. (2-tailed)	,017

a. Grouping Variable: GRUP

- The statistical test shows again no significant difference.
- Although the situation is getting worse, a relative good score and an improvement was also seen at the second set of items: reason for referral. Media here was 2,05 for 2010 and 2,6 for 2011 out of 4 maximal point sum.

The Score for Background Information in 2010 and 2011

Ranks

	GRUP	N	Mean Rank	Sum of Ranks
Background info	DR 2010	55	53,75	2956,50
	DR 2011	55	57,25	3148,50
	Total	110		

Test Statistics[a]

	background
Mann-Whitney U	1416,500
Wilcoxon W	2956,500
Z	-,597
Asymp. Sig. (2-tailed)	,550

a. Grouping Variable: GRUP

- No significant difference.
- The third set of items, social status and other background information shows a relatively low score both for 2010 and 2011 (1,38 and 1,47) and again the maximum score would be 4.

Symptoms scoring for 2010 and 2011

Ranks

	GRUP	N	Mean Rank	Sum of Ranks
aktuelt	DR 2010	55	49,32	2712,50
	DR 2011	55	61,68	3392,50
	Total	110		

Test Statistics[a]

	aktuelt
Mann-Whitney U	1172,500
Wilcoxon W	2712,500
Z	-2,086
Asymp. Sig. (2-tailed)	,037

a. Grouping Variable: GRUP

- A little bit better is the situation for the fourth set of items, symptoms and other relevant information. Here media for 2010 is 1,78 and the situation seems better for 2011 with a media of 2,29 (out of 4 maximal points of course) which is not significant

from a statistical perspective but it is an improvement. Yet a qualitative evaluation on the charts will show that 20% of the family doctors did not mention a single symptom and that in my professional opinion is not acceptable; you cannot refer a child to a psychiatric clinic based on no symptoms.

Somatic Status Score for 2010 and 2011

Ranks

	GRUP	N	Mean Rank	Sum of Ranks
Somatic status	DR 2010	55	48,39	2661,50
	DR 2011	55	62,61	3443,50
	Total	110		

Test Statistics[a]

	Somatic status
Mann-Whitney U	1121,500
Wilcoxon W	2661,500
Z	-2,431
Asymp. Sig. (2-tailed)	,015

a. Grouping Variable: GRUP

- The statistic test is not significant
- The situation becomes worse at this next set of items referring to somatic status of the patient. Media was 1,07 out of 4 maximal point sum.

Other interventions

Ranks

	GRUP	N	Mean Rank	Sum of Ranks
Other interv	DR 2010	55	54,49	2997,00
	DR 2011	55	56,51	3108,00
	Total	110		

Test Statistics[a]

	Other interv
Mann-Whitney U	1457,000
Wilcoxon W	2997,000
Z	-,379
Asymp. Sig. (2-tailed)	,705

a. Grouping Variable: GRUP

- No significant difference.
- The worst results come at the last set of items, other interventions related to this episode or to previous episodes. In this case the media was 0,95 for 2010 and 0,96 for 2011.

Considering that the scores of the factors vary a lot where the first factor (pure demographic information that do not influence the decision in regarding the right to specialize medical care) is significant higher than the other factors, I decided calculate the *real score* which does not include the first factor. As expected media of *the total score* looks better than the one for *the real score:*

	The total score media	The real score media
2010	10,71	7,21
2011	12,62	8,96

2. The Patient Perspective

2.1. Case Study

Evaluation of admittance into psychiatric health units. Case 1. JKW

The patient was referred to psychiatric health services for the first time in November 2006. At that time has been evaluated that the patient has the right to needful help and JKW began treatment in February 2007 at The Psychiatric Clinic for Children and Youth Hamar. Because the family moved to far away district, the case was transfer to another clinic in August 2008.

Despite the recommendation from the last named clinic that the district responsible (the family was moving back) should get involved in the case and elaborate an individual plan for the patient, the district decided to refer the case again to the psychiatric clinic in March 2010.

As a consequence was the case rejected and referred further to The Child Protection with concern for the parents ability to take care of the child.

It was issued an appeal and the case was evaluated again in December 2010 with the same result.

In February 2011 the case was referred again to the psychiatric services. Since the home situation was practically the same and there was no indication that the child has symptoms that need psychiatric intervention, the case was rejected again. In addition, The Child Protection was conducting an investigation in the same time, which made it even more inappropriate to interfere in the process.

It was issued another appeal. This time was the family lawyer who took the initiative. Although the home situation was the same, the were no sign for psychiatric pain with the child and the investigation was in the process with The Child Department, the decision this time was totally different and in March 2011 The Psychiatric Clinic for Children and Youth decided that patient has the right to specialized needful help.

In this particular case, it is interesting to find out what happened next.

JKW and the family were invited to first meeting 24th June 2011. They did not come to this meeting because they overslept. In fact, out of 7 (seven) meetings they manage just 3 (three) despite the fact that they received clear messages and SMS notice 24hours before the meeting.

There were other numerous facts that showed unwillingness to cooperate from family side, such as father's denial to participate to any of those meetings. The case was closed due noncooperation of the family.

From a humanitarian perspective, it has to be said that several employees expressed their frustration when it comes to JKW case. On the one hand, there is a child who needs a foster family and on the other hand, there are the parents who cannot take care of their child but hire a lawyer to fight against all instances. And in between them there are Social Services, The Child Protection, The Psychiatric Clinic for Children and Youth and maybe some other instances that struggle to do their best in order to provide qualitative services while they are threatened by the family's lawyer.

From an economical perspective, there is almost needless to say that at least the employees from The Psychiatric Clinic did a meaningless job, which cost society a lot of money unnecessarily.

From a medical perspective, it is easy to understand that another child/ family who were entitle to medical needful help was force to wait in line.

Evaluation of admittance into psychiatric health units. Case 2 MT

The case was referred by The Child Protection because MT showed symptoms for attachment disorder, but those symptoms are not mention in the referral. The child and sister have been set together in a foster family, but MT is now moving to another foster family.

The parents was not able to provide good enough care for their children, but we do not know why; what did happen in the family; are the parents still alive; were the children abused; have the children been expose to violence and so on. Those questions did not receive any answer.

The foster family situation is not known either; why is the sister still in their care while MT has to be set in another foster family; did they try to resolve whatever problems they might have in the family in order to help MT; if so, how; is there any reason to believe that the symptoms are going to persist even after the child will move to the other foster family; if so, why. Neither those questions were answered.

Although moving from one family to another is a stressful situation for a child, there are no clear indications that MT has psychiatric symptoms to justify admittance into a psychiatric facility center. In fact, the family doctor does not give any reason for referral. It has been named some compartmental issues in the past and some learning's problems.

This is a typical case to exemplify how the system fails the patient. In this case, there are natural reasons to believe that the patient might need specialized medical help, but the referral fail to give enough information that will support the "natural reasons".

Evaluation of admittance into psychiatric health units. Case 3 Siblings H.

Three children are caught in war between the mother and father. This is clearly a case for the family office. There are no psychiatric symptoms with any of those three children. They react to circumstance. The reactions most probably will disappear if the circumstances would change. The divorce is taking too long to be finished, the lawyer fight blindly on behalf of the parents, the parents themselves fight blindly for their children's love.

The Child Protection, The Family Office tried to help the parents reach a compromise, but because negotiation failed they decide to refer their cases further to The Children Psychiatric Clinic.

This is another typical case that exemplifies the deficient collaboration between different instances in the health department. In this controversial case, The Children Psychiatric Clinic must take over the cases despite the fact that there is no evidence at all for psychiatric symptoms, but because The Family Office failed to do the job.

Evaluation of admittance into psychiatric health units. Case 4 JSE

In the February 2011, ten years old JSE was refer to The Children Psychiatric Clinic because the child has problem to concentrate, to focus, to understand verbal communication, to learn, to play with other children, to follow social rules. Based on these descriptions, the family doctor referred the girl to the specialist and the reason was then suspicion on hyperkinetic condition.

The case was rejected by the committee in charge with the admittance of patients because suspicion on hyperkinetic conditions should be first evaluated by The Psycho Pedagogical Unit associated to this particular school in order to investigated if there are some other reason that justify the child lack of concentration and learning difficulties.

Six months later, the family doctor sends a new referral. The situation is the same, the child have the same problems at school: difficulties to concentrate, difficulties to understand verbal messages, learning difficulties, social difficulties and so on. Despite that, the referral's reason is different this time: suspicion on oppositional defiant disorder.

In addition, there is no rapport from PPT (psycho pedagogic services) attached to the referral if such rapport has been conducted. Instead, two teachers send a declaration where they show their concerns about the child because of those symptoms mentioned above.

This case presents us couple of dilemmas: how should we pursue the school or more exact schoolteachers that are in charge in a specific situation to follow the recommendation of the specialist? How to pursue the family doctor to give the argument for his/hers suspicion especially when s/he decide to change the medical reason for referral?

In the mean time, the child is struggling to cope with the problems – whatever the problems are. There is no reason either to believe that the child's condition is fortunate, nor to believe that the child needs indeed psychiatric help, as the referrals are formulated.

It is also not mention why the school chooses not to involve the psycho pedagogical services, or why the rapport from this instance is not sent with the referral to the specialist if indeed psycho pedagogical services were involved.

This child has no other chance but suffering alone caught in between school, PPT, BUP and family doctor. And that is, in my opinion unethical. Why this child and the family must suffer?

Evaluation of admittance to psychiatric health units. Case 5 HS

This case is a very good example on how a referral should be written and that despite the fact that the medical doctor who wrote it did not followed the standard procedure and did not use the recommended form for referral.

It is easy to get the information you need in order to evaluate the case. It is clear the motive for referral and the description of symptoms that argue the referral is adequate and concise. The child's symptoms worried the family doctor and on suspicion on anxiety disorder refer the case to a specialist.

The case was so good argued and therefore so easy to be evaluated that the decision came quickly in everybody's mind: yes, the child has the right to specialized health care in a psychiatric clinic.

2.2. The Second Project – Parallel Evaluation of Referral by Decision Makers

This project is attempting to find out how different decision makers evaluate same referral. The 20 referrals have been evaluated by six different teams of decision makers from six different psychiatric clinics. I want to see if the decisions are influence or not by the human factor. The null hypothesis is postulate that there is no significant difference between the way a referral is evaluated.

CROSSTABS – Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
BUP Hamar * BUP Lillehammer	20	100,0%	0	,0%	20	100,0%
BUP Hamar * BUP Gjovik	20	100,0%	0	,0%	20	100,0%
BUP Hamar * BUP Elverum	20	100,0%	0	,0%	20	100,0%
BUP Tynset * BUP Lillehammer	20	100,0%	0	,0%	20	100,0%
BUP Tynset * BUP Gjovik	20	100,0%	0	,0%	20	100,0%
BUP Tynset * BUP Elverum	20	100,0%	0	,0%	20	100,0%
BUP Kongsvinger * BUP Lillehammer	20	100,0%	0	,0%	20	100,0%
BUP Kongsvinger * BUP Gjovik	20	100,0%	0	,0%	20	100,0%
BUP Kongsvinger * BUP Elverum	20	100,0%	0	,0%	20	100,0%

BUP Hamar * BUP Lillehammer - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	,317[a]	1	,573		
Continuity Correction[b]	,000	1	1,000		
Likelihood Ratio	,307	1	,580		
Fisher's Exact Test				,613	,483
Linear-by-Linear Association	,302	1	,583		
N of Valid Cases	20				

a. 3 cells (75,0%) have expected count less than 5. The minimum expected count is 1,50.

b. Computed only for a 2x2 table

BUP Hamar * BUP Gjovik - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	2,756[a]	2	,252
Likelihood Ratio	2,808	2	,246
Linear-by-Linear Association	1,333	1	,248
N of Valid Cases	20		

a. 5 cells (83,3%) have expected count less than 5. The minimum expected count is 1,00.

BUP Hamar * BUP Elverum - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	,351[a]	1	,554		
Continuity Correction[b]	,000	1	1,000		
Likelihood Ratio	,593	1	,441		
Fisher's Exact Test				1,000	,750
Linear-by-Linear Association	,333	1	,564		
N of Valid Cases	20				

a. 3 cells (75,0%) have expected count less than 5. The minimum expected count is ,25.

b. Computed only for a 2x2 table

BUP Tynset * BUP Lillehammer - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	2,468[a]	2	,291
Likelihood Ratio	3,226	2	,199
Linear-by-Linear Association	,151	1	,698
N of Valid Cases	20		

a. 5 cells (83,3%) have expected count less than 5. The minimum expected count is ,90.

BUP Tynset * BUP Gjovik - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1,758[a]	4	,780
Likelihood Ratio	2,295	4	,682
Linear-by-Linear Association	,019	1	,892
N of Valid Cases	20		

a. 8 cells (88,9%) have expected count less than 5. The minimum expected count is ,60.

BUP Tynset * BUP Elverum - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	,861[a]	2	,650
Likelihood Ratio	1,239	2	,538
Linear-by-Linear Association	,667	1	,414
N of Valid Cases	20		

a. 4 cells (66,7%) have expected count less than 5. The minimum expected count is ,15.

BUP Kongsvinger * BUP Lillehammer - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	2,540[a]	1	,111		
Continuity Correction[b]	1,200	1	,273		
Likelihood Ratio	2,531	1	,112		
Fisher's Exact Test				,161	,137
Linear-by-Linear €Association	2,413	1	,120		
N of Valid Cases	20				

a. 2 cells (50,0%) have expected count less than 5. The minimum expected count is 2,40.

b. Computed only for a 2x2 table

BUP Kongsvinger * BUP Gjovik - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3,958[a]	2	,138
Likelihood Ratio	4,096	2	,129
Linear-by-Linear Association	1,760	1	,185
N of Valid Cases	20		

a. 5 cells (83,3%) have expected count less than 5. The minimum expected count is 1,60.

BUP Kongsvinger * BUP Elverum - Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	1,579[a]	1	,209		
Continuity Correction[b]	,044	1	,834		
Likelihood Ratio	1,912	1	,167		
Fisher's Exact Test				,400	,400
Linear-by-Linear Association	1,500	1	,221		
N of Valid Cases	20				

a. 2 cells (50,0%) have expected count less than 5. The minimum expected count is ,40.

b. Computed only for a 2x2 table

Test Statistics

	BUP Hamar	BUP Tynset	BUP Kongsvinger	BUP Lillehammer	BUP Gjovik	BUP Elverum
Chi-Square	5,000[a]	4,900[b]	,800[a]	3,200[a]	2,800[b]	16,200[a]
df	1	2	1	1	2	1
Asymp. Sig.	,025	,086	,371	,074	,247	,000

a. 0 cells (,0%) have expected frequencies less than 5. The minimum expected cell frequency is 10,0.

b. 0 cells (,0%) have expected frequencies less than 5. The minimum expected cell frequency is 6,7.

Analyzing the results from ‘chi-square test statistics’ lead us to the conclusion that there is a significant difference between the expected frequencies and observed frequencies in The Elverum Children Psychiatric Clinic (BUP Elverum) with respect to the evaluation of referrals of patients.

Even though the hypothesis was supported – there is no difference in the way a referral is evaluated – in the case of the other five clinics that cannot prove that the hypothesis is true, simply because this samples might be atypical. Repeated sampling may show a significant difference or eliminate the difference been showed now.

In addition, a qualitative analysis where every single case is taking under consideration shows that only 5 out of 20 referrals were evaluated in the same way by all the decision makers.

CONCLUSION

The topic of equality and equitable in health care services or society in more generals terms, is on debate since Euripides' time and I do not pretend that I solve it hic et nunc. When it comes to our responsibility toward other people common sense seems to be a way to deal with it. I remember an interesting statements that came from a mental patient who said: 'everybody is talking about how to reduce involuntary hospitalization of mental patients, but nobody realizes that these waiting list 'are forcing' involuntary hospitalization'.

There is one aspect though in which the majority of the subjects agrees on, we do need more medical doctors and fewer decision makers.

We, people are selfish and greed, we want first and best for ourselves, we want the largest piece of pie from the common well fare. No one is voluntarily happy to sacrifice self best for the sake of society; some will do it, but nobody wants to.

My aim was to find out how ethical it is to prioritize between patients, or in more dramatic words how ethical it is to decide who lives and who dies. And I find out that is not. I also find out that we call this life. I find out that life is not fair nor unfair, life is just is, and each individual should make the best of it. Nobody should wait for treatment, nobody should be denied treatment and nobody should have to live with the responsibility of making this decision.

But I am happy to find out that people work hard in order to do a good job for their patients. It is somehow comforting to know that people care about it, that they are doing their best.

I am not happy to find out that is a great consolation between decision makers that there are only *few* patients… that have to wait, or that do not receive the right to be prioritize. Well I imagine that for those particular *few* patients or their families that being one of *few* is not a helpful thought. I am quite sure that they have trouble finding the positive side of this situation and most probably they are preoccupied to find answers to some questions like *why not me? why this happens to me?*

When it comes to our responsibility toward other people common sense seems to be a way to deal with it and we have to hope that other people will use common sense too. I guess that is why hope is as popular today as it was when it gets out from Pandora's Box.

One thing it is missing from this frame: the honesty of the policy, the decency of saying the truth to the tax-payers. I believe that it is only fair to inform the tax-payers that when they might need the tax-paid services there is a chance, quite small but significant, of not receiving these services. People have the right to know that they should wait in line for treatment weeks and months; people have the right to know that some medical treatments are considered too expensive and therefore not offered even though the alternative treatment is not efficient; people have to right to know that whoever complains harder have more chances to receive treatment quicker. In a fewer words I could say that I honestly believe that the well fare state is not that fair, after all.

If you take a round in Norwegian health care facilities, you will most probably be amazed to see all over the walls information about how good it is to be a patient in Norway; how many rights you, as patient you have; how many and how good facilities you could expect at any given time. Anyway, there is no poster, no brochure that will inform you what will happen with you if you do not get to be a patient; nor how many of us end up in that situation, where you feel sick, but some decision makers are not convince by the referral that you actually need specialized health care. That should be a funny poster and I am quite sure that will have a lot of readers. Unfortunately, people do not find out about this before they receive the letter with a negative answer that will inform them with respect that their case was evaluated with deep sympathy and all seriousity and considering the information provided in referral the criteria for specialized care are not fulfill and therefore the case was rejected. For many people, such letter comes as a shock. They were prepare to wait, because they were inform not by mass media about that, but they are not prepared to be rejected. And what exactly are you suppose to do when you find out that you are left outside the system? Be angry? Cry? Forget the pain? Think positive?

Most probably, some of the people that are rejected do not need medical treatment, but some of them do. Some people could get through without medical care, with this I mean that they might have some problems, but they could use free from prescription medications or some other alternative methods with significant and similar effects.

But some people that have been rejected are indeed needing specialized medical services, and things go from bad to worst in most of the cases, so what happens with them?

A strange situation is created when patients are suffering, media is revolted while health politicians and managers are avoiding direct response. Of course this avoidance behavior is not documented but a sign that health policy makers are avoiding responsibility for waiting time is lack of systematic information. Of all four regions is only the central part of Norway that provide accurate and easy access data on this subject.

This paper does not have the aim to find solution nor to resolve the problems of prioritizing and waiting list. A social perspective upon an economical aspect struggles always to capture rational attitudes. The truth is that we are more likely to be rational about sexual desire than spending money. In addition this paper is based mostly on qualitative methods and therefore it is not representative for the entire population. This is just a preliminary research and there is definitely a need for more advance fact-findings both in general but also in Norwegian setting.

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APPENDIX 1

Statistisk sentralbyrå
Statistics Norway

2 Pasienter med legekontakt, etter kommunetype. Absolutte tall og prosent. 2005

Kontaktrate	Pasienter		Kommunetype					
	Antall	Prosent	Mindre sentral		Sentral		Mest sentral	
			Antall	Prosent	Antall	Prosent	Antall	Prosent
I alt	52 325	100	8 911	100	22 982	100	20 432	100
En kontakt	26 440	51	4 927	55	10 995	48	10 518	51
To kontakter	10 959	21	1 774	20	4 841	21	4 344	21
Tre kontakter	5 846	11	927	10	2 681	12	2 238	11
Fire kontakter	3 301	6	488	5	1 546	7	1 267	6
Fem kontakter	2 082	4	320	4	967	4	795	4
06 - 10 kontakter	3 139	6	413	5	1 640	7	1 086	5
11 og flere	558	1	62	1	312	1	184	1

Standardtegn i tabeller

4 Pasientkontakter med diagnose[1], etter diagnosegrupper og kjønn. Absolutte tall og prosent. 2005

Diagnoser	Begge kjønn		Menn		Kvinner		Ukjent	
	Antall	Prosent	Antall	Prosent	Antall	Prosent	Antall	Prosent
I alt	109 826	100	43 741	100	65 987	100	98	100
01 Luftveisinfeksjoner, inkl. ørebetennelse	10 093	9	4 117	9	5 961	9	15	15
02 Lokale smerter og betennelser	7 193	7	2 952	7	4 241	6	-	-
03 Ryggproblemer	4 779	4	2 208	5	2 570	4	1	1
04 Generelle smerter og muskelplager	1 605	1	340	1	1 265	2	-	-
05 Ledd- og giktsykdommer	2 929	3	845	2	2 084	3	-	-
06 Psykisk sykdom eller lidelse	13 469	12	5 555	13	7 908	12	6	6
07 Atopi, astma, allergi eller eksem	2 645	2	1 170	3	1 472	2	3	3
08 Høyt blodtrykk	4 391	4	1 962	4	2 428	4	1	1
09 Hjertesykdom	5 567	5	2 974	7	2 591	4	2	2
10 Diabetes	2 079	2	1 071	2	1 008	2	-	-
11 Kreft	1 591	1	850	2	740	1	1	1
12 Underlivsplager hos kvinner	1 608	1	-	-	1 607	2	1	1
13 Funksjonelle mage-tarmplager	3 388	3	1 470	3	1 914	3	4	4
14 Hudinfeksjoner	1 456	1	716	2	735	1	5	5
15 Ulykker og skader	3 357	3	1 742	4	1 603	2	12	12
16 Medfødt sykdom eller feil	239	0	123	0	116	0	-	-
17 Svangerskap, fødsel, prevensjon	4 092	4	-	-	4 092	6	-	-
18 Frykt for sykdom	553	1	253	1	297	0	3	3
19 Administrativ el. forebyggende kontakt	3 057	3	1 076	2	1 969	3	12	12
20 Andre diagnoser	35 735	33	14 317	33	21 386	32	32	33

Diagnoser	Begge kjønn		Menn		Kvinner		Ukjent	
	Antall	Prosent	Antall	Prosent	Antall	Prosent	Antall	Prosent

[1] Kontakter med hoveddiagnose

Opplevelse av psykiske plager siste 14 dager. Prosent av voksne i alderen 16-79 år. Veid utvalg. 1998

	Ikke plaget	Litt plaget	Ganske mye plaget	Veldig mye plaget	N
Hodepine	50,3	38,7	8,0	3,1	6 637
Skjelving	89,0	9,1	1,2	0,6	6 623
Matthet eller svimmelhet	68,4	26,6	4,0	1,0	6 625
Nervøsitet, indre uro	65,2	27,7	5,4	1,7	6 640
Plutselig frykt uten grunn	88,7	8,9	1,6	0,8	6 637
Stadig redd eller engstelig	86,3	10,9	2,0	0,8	6 633
Hjertebank	81,4	15,5	2,4	0,7	6 638
Vært anspent, oppjaget	56,2	36,7	5,7	1,4	6 624
Anfall av angst, panikk	91,2	7,0	1,0	0,7	6 639
Rastløs, vansker med å sitte i ro	75,5	20,6	2,9	1,0	6 636

Mangel på energi, alt går langsomt	52,0	37,3	7,9	2,8	6 638
Lett for å klandre seg selv	61,8	29,8	6,2	2,1	6 610
Lett for å gråte	75,0	19,6	3,8	1,6	6 641
Dårlig matlyst	84,7	12,2	2,4	0,7	6 645
Søvnproblemer	62,3	27,8	6,8	3,1	6 656
Håpløshet med tanke på fremtiden	71,7	21,3	4,3	2,7	6 636
Nedtrykt, tungsindig	73,1	21,8	3,8	1,3	6 614
Følelse av ensomhet	74,4	19,7	4,0	1,9	6 640
Følelsen av å være lurt i en felle	90,6	7,2	1,3	0,9	6 611
Mye bekymret eller urolig	64,9	28,3	5,0	1,9	6 639
Uten interesse for noe	84,6	12,6	2,0	0,9	6 630
Følelse av at alt er et slit	63,6	28,9	5,0	2,5	6 641
Følelse av å være unyttig	82,5	12,9	2,7	1,8	6 640

Kilde: Helseundersøkelsene, Statistisk sentralbyrå.

Et utvalg enkeltdiagnoser (koder) som registreres ofte hos allmennlegen, sortert for hhv. menn og kvinner

Menn		**Kvinner**	
IPCP-kode	Diagnose	IPCP-kode	Diagnose
K86	Hypertensjon ukomplisert	P76	Depressiv lidelse
P76	Depressiv lidelse	K86	Hypertensjon ukomplisert
K78	Atrieflimmer/flutter	W781	Svangerskapskontroll
T90	Diabetes, ikke-insulinavhengig	A29	Generelle symptomer/plager IKA
A97	Administrativ kontakt/undersøkelse	U71	Cystitt/urinveisinfeksjon IKA
R74	Akutt øvre luftveisinfeksjon	R74	Akutt øvre luftveisinfeksjon
L86	Ryggsyndrom med smerteutstråling	A97	Administrativ kontakt/undersøkelse
A29	Generelle symptomer/plager IKA	L18	Utbredte muskelsmerter/fibromyalgi
L84	Ryggsyndrom uten smerteutstråling	R05	Hoste

R05	Hoste	T90	Diabetes, ikke-insulinavhengig
K76	Iskemisk hjertesykdom, kronisk IKA	K78	Atrieflimmer/flutter
P19	Stoffmisbruk	L92	Skuldersyndrom
R80	Influensa	A04	Slapphet/tretthet
L92	Skuldersyndrom	L86	Ryggsyndrom med smerteutstråling
R96	Astma	P74	Angstlidelse
L02	Rygg symptomer/-plager	L88	Reumatoid artritt/reumatisk sykdom
P06	Søvnforstyrrelse	P06	Søvnforstyrrelse
R83	Luftveisinfeksjon IKA	R80	Influensa
K90	Hjerneslag	R75	Bihulebetennelse
P74	Angstlidelse	L84	Ryggsyndrom uten smerteutstråling

Selvmord, etter kjønn 2005

Menn. Alle selvmord	360
Kvinner. Alle selvmord	173

4.21 Behandlede pasienter i sykehus, sykestuer og fødehjem

	I alt		Alm. somatiske sykehus og spesialsykehus		Sykestue og/eller fødehjem		Psykiatriske sykehus	
	Behandlede pasienter	**Per 100 000 innbyggere**	**Behandlede pasienter**	**Per 100 000 innbyggere**	**Behandlede pasienter**	**Per 100 000 innbyggere**	**Behandlede pasienter**	**Per 100 000 innbyggere**
1977	598 500	14 773	572 276	14 126	9 055	224	17 169	424
.....								
2004	806 565	17 510	793 203	17 220	5 274	114	8 088	176
2005[2]	838 633	18 073	806 466	17 380	4 822	104	27 345	589

[1] Fra 1992 er det for de somatiske sykehusene brukt opplysninger fra pasientregisteret i stedet for skjema. Antall døgnopphold for bosatte i Norge.

[2] Fra 2005 er det summen av psykiatriske sykehus og klinikkavdelinger.

Kilde: Statistisk sentralbyrå. NOS Helseinstitusjoner og www.ssb.no/sykehus.

Sysselsatte i helse- og sosialnæringer, etter region, utdanningsnivå, alder, næring (SN2007), tid og statistikkvariabel

Personer med helse- og sosialfaglig utdanning, etter arbeidsstyrkestatus, statistikkvariabel, tid, alder og fagutdanning

Alle aldre

	Helsesekretærer	Hjelpepleiere	Omsorgsarbeidere	Apotekteknikere	Fotterapeuter	Barne- og ungdomsarbeidere	Tannhelsesekretærer	Aktivitører	Annen videregående helseutdanning	Ergoterapeuter	Fysioterapeuter	Helsesøstre og jordmødre	Radiografer	Sykepleiere	Vernepleiere	Tannpleiere	Bioingeniører	Barnevernspedagoger	Sosionomer	Øvrig helseutdanning med høgskole	Reseptarer, reseptarfarmasøyter og provisorfarmasøyter	Leger uten spesialitet	Leger med spesialitet	Tannleger	Psykologer	Øvrig helseutdanning på universitetsnivå
Lønnstakere																										
Personer																										
2005	7 371	67 879	14 047	4 138	803	13 123	3 701	3 536	3 923	2 800	5 651	5 744	2 257	76 039	9 068	906	5 257	6 651	8 841	3 957	2 928	7 533	7 749	2 222	4 190	795
Selvstendig næringsdrivende																										
Personer																										
2005	102	1 471	156	40	580	189	81	114	280	43	3 458	95	5	1 192	72	98	65	110	145	168	93	1 485	2 835	2 091	654	276
Registrerte arbeidsledige																										
Personer																										
2005	237	768	244	101	49	313	76	76	38	44	67	14	24	303	57	11	54	100	117	39	14	44	5	8	26	13

Fotnote(r):

For en nærmere omtale av kvaliteten på endringstallene mellom årgangene vises til 'Om statistikken' på ssb.no/emner/06/01/hesospers.
På grunn av strengere krav til bruttoinntekt for selvstendig næringsdrivende vil det være brudd i antall selvstendig næringsdrivende mellom 2001 og 2002.
Årgangene 2005 og 2006 ble revidert april 2008 . For nærmere informasjon se 'Om statistikken'.

fagutdanning
Leger uten spesialitet
Medisinstudenter med lisens er inkludert.

APPENDIX 2

DAGSREVYEN 21 07.03.2011

In the Norwegian bulletin report from 7th March 2011 (Dagsrevyen 21. Nyhetsmagasin med Norge i dag og sport) at the national television NRK was presented a news:

”De som røyker og drikker mye og ikke hører på helseråd bør prioriteres lavere i helsevesenet, mener mange leger. En ny undersøkelse viser at 45% av norske leger åpner for en slik forskjellsbehandling. Er norske leger i ferd med å bli lei av folk som ikke lytter til helseråd? Mye kan tyde på det. En ny undersøkelse viser at mange norske leger er åpner for å straffe deg som får lyst til sykdommer.

Eli Feiring, førsteamanuensis i helsepolitikk ved UiO: *Det vår undersøkelse viser er at cirka 45% av norske leger ikke stiller seg avvisende, til å diskutere i hvert fall om eget ansvar skal få betydning i prioritering sammenheng.*

Kåre Reiten, allmennlege: *De fleste av mine kollegaer mener jo at vi skal behandle folk likt, men de klarer ved sitt hver dag å se at pasienter lever på en måte som ødelegger helsen dere og vi kunne gjerne i en del situasjoner tenke oss å kunne sette et litt større krav til pasientene.*

I tillegg til røyk er alkohol og usunne matvaner det som skaper størst bekymring blant norske leger. At så mange åpner for å forskjellsbehandle sunne og usunne pasienter overrasker forskerne og uroer legeforeninger. De slår fast at alle pasientene i Norge skal få lik behandling.

Toruun Janbu, president, Det norske legeforeningen: *Det er veldig viktig å poengtere at den samme gruppen leger sier altså helt tydelig at de ikke vil gi forskjellige helsehjelp.*

Kåre Reiten: *Uansett hva man gjør med innskrenka på, lar meg si noe tilbud i befolkninga, ser man dessverre alltid de svakeste som blir rammet. Og det er dilemma men vi kan ikke dermed oppgi å forsøke noe.*”

Appendix 3

THE DISCRETE CHOICE EXERCISE – SURVEY AT THE INSTITUTE FOR HEALTH ECONOMICS AND MANAGEMENT, UNIVERSITY OF OSLO, 2010

Question: if these were your only options, which would you choose? Check one of the options below:

Severity of disease	Not severe Health expectancy <>2 years without intervention	Severe Health expectancy <2 years without intervention
Number of potential beneficiaries	Few (<100,000)	Many (>100,000)
Age of target group	Young (0 to 14 years)	Elderly (>60 years)
Individual health benefits	Small (<5 healthy years)	Large (>5 healthy years)
Willingness to subsidize others	Less than 70% of total health expenditure	More than 70% of total health expenditure
Cost-effectiveness	Cost effective (Cost/DALY < 1* GDP/cap)	Not cost effective (Cost/DALY > 1*GDP/cap)
	☐	☐

APPENDIX 4

INTERVJUET MED BESLUTNINGSTAKERE OM PRIORITERING AV PASIENTER

1. Hva mener du når det gjelder prioritering av pasienter?
2. Synes du at det er nødvendig å prioritere?
3. Synes du at det er rettferdig? Er det etisk?
4. Synes du at det lettere eller vanskeligere å prioritere innen mental helse sammenlignet med somatiske felte?
   4.1. Hvilken erfaring har du i det medisinske feltet?
   4.2. Hvor sikker er du når du setter en diagnose?
   4.3. Hvor mange ganger måtte du forandre en diagnose?
5. Hvilken informasjon trenger man for å kunne avgjøre rekkefølgen av pasientene?
   5.1. Fastlegens vurdering. Hvor mye kan du stole på det?
   5.2. Din egen erfaring. Hvor mye kan du stole på det?
   5.3. Annet?
6. Hvor lang venteliste har dere? Finnes det noe statistikk på dette?
7. Hvilke konsekvenser får det for denne pasienten som er et barn og som må vente opp til 12 uker for behandling?
8. Hva om det er deg som er syk og trenger behandling?
   8.1. Ville du da ofre din helse for fellesskapet beste?
   8.2. Hvor mange dager ville du vente på behandling? Og hvor syk må du være for å kunne bli den første på listen? For å være prioritert?
   8.3. Hvilken helseeffekt er svak nok fra ditt perspektiv sånn at det ikke lønner seg for deg å følge behandlingen?
   8.4. Hvor mye skulle samfunnet betale for din egen helse behov? Hvor mye for at din helse blir 10% bedre?
9. Hvordan rettferdiggjør du forskjellen mellom beslutningstakeren og den som blir "glemt" i systemet i en verden der alle er født like i utgangspunktet? Med andre ord, hvordan rettferdiggjør du ditt privilegium til å ta avgjørelser som angår en annen persons liv? Hvilken filosofi underbygger prioriteringsprosessen?

APPENDIX 5

PROSJEKT HENVISNINGER TIL BUP – SOM LEDD I Å FORBEDRE SAMHANDLING

Prosjektet i samarbeid med BUP Hamar og praksiskonsulent Ragnhild Dybvig, mars 2011

Henvisninger til Barne- og ungdomspsykiatrisk poliklinikk blir vurdert i henhold til prioriteringsveilederen ”Psykisk helsevern for barn og unge”. Det er viktig at nødvendige opplysninger foreligger i henvisningen, slik at vurderingen ikke forsinkes og prioriteringen blir rett i forhold til hvem som trenger utredning og eventuelt behandling i spesialisthelsetjeneste.

+ Marker informasjonen som **ble funnet** i henvisningen

- Marker informasjonen **som mangler** i henvisningen

1. Navn og adresse
    a. barnet
    b. mor
    c. far
    d. annen omsorgsperson (f eks fosterforeldre)
2. Samtykke
    a. mor
    b. far
    c. barnet selv (over 16år)

3. Symptombeskrivelse

    a. symptomer i møte med legen

    b. symptomer beskrevet av foreldre i hjemme/fritid situasjonen

    c. symptomene opplevd av barnet selv (jo eldre barnet er desto mer relevant blir det)

    d. symptomene opplevd av skole/SFO/barnehage

4. Hva slags førstelinjetiltak er blitt forsøkt for å avhjelpe de problemene barnet henvises for?

    a. PP Tjeneste

    b. Barnevern

    c. Helsestasjon/ skolehelsestasjon

    d. Annet

5. Hvem arbeider med saken nå?

    a. PP Tjeneste

    b. Barnevern

    c. Helsestasjon/ skolehelsestasjon

    d. Annet

6. Legens egen vurdering av aktuelle symptomer, somatisk status, eventuelle andre medvirkende forhold til symptomene som fysisk helse, mobbing, vansker med skolefag/ læring, sosiale forhold som vold, fattigdom, alkohol, annet:_____

7. Hva ønskes det hjelp til:_____

8. Klientens behandlingsmotivasjon: _____